CHAPTER I.1. INTRODUCTION TO THE COST OF ILLNESS HANDBOOK

Clicking on the sections below will take you to the relevant text.

CHAPTER I.1. INTRODUCTION TO THE COST OF ILLNESS HANDBOOK

This handbook is provided through EPA's website. All chapters in the handbook have links to this chapter because it contains basic information on objectives, content of the handbook, analytical methodology, limitations, and results. It is anticipated that the web site will be updated continuously and this chapter will be modified as new information becomes available. As shown in the example below, you can use sidebars appearing at the left to link to resources that may be useful while reading and using the Chapters. These include the table of contents (which can be used to link to any chapter), a glossary with abbreviation definitions, inflation and discounting factors, an executive summary, and other useful websites (e.g., OPPT).

Sidebar example:
Click here to link to the Table of Contents

The cost of illness is an estimate of the incremental direct medical costs associated with medical diagnosis, treatment, and follow-up care. This includes various cost elements, such as physician visits, hospitalization, and pharmaceuticals. This Handbook does not estimate the costs in lost time or wages that may be incurred by either a patient or his or her unpaid caregiver. The costs also do not include pain and suffering, which may be substantial. Rather, this Handbook provides information on medical treatments and their costs, usually aggregated over the lifetime of the patient. These costs are inflated to the current year, and summarized at various discount rates.[1] A discussion of willingness-to-pay, which is presented later in this chapter, outlines in more detail the cost elements that are and are not included in the Handbook.

A normative approach is used to estimate costs, whereby the average age at diagnosis, the average life expectancy, and other average or mean values are used to estimate costs. The text notes situations which may arise that would lead to higher or lower costs than those estimated in this Handbook.

Due to the variability in medical costs geographically and over time, there is considerable uncertainty associated with estimating direct medical costs. An estimate of costs is often useful, however, when considering planning, decision-making, and regulatory development. As such, it can provide an efficient lower-bound estimate of the benefits of avoiding an illness.

[1] The chapters were developed over many years and the costs are presented in the current dollar value for the year the chapters were written. Inflation factors based on the Consumer Price Index can be accessed by clicking on the lefthand sidebar and used to inflate the costs to any year up to the present.

Link to inflation factors: Appendix A

I.1.A Overview

Improvements in human health in the form of avoiding adverse health effects frequently constitute a major portion of the benefits resulting from environmental regulations. There are a variety of approaches to estimating the value of these benefits, but one of the simplest and more straightforward approaches is to calculate the medical and related costs avoided because of the health improvements.

The purpose of this handbook is to present information on the direct medical costs resulting from illnesses that are associated with exposure to environmental agents.[2] These cost data can be used for policy and regulatory development and evaluation, benefits assessments (e.g., RIAs), and other applications where there is interest in either medical costs avoided due to pollution prevention or costs incurred due to a lack of pollution control. Direct medical costs represent only a portion of the total benefits associated with pollution prevention/reduction, but in many cases these lower-bound estimates may be sufficient for decision-making purposes.

This handbook has been developed over many years, beginning in 1991. The level of sophistication and complexity in the field of health economics has evolved and the approaches taken in the chapters has likewise evolved. In addition, the needs of the Agency and the requirements of benefit cost analysis have changed with the advancing field of economics. To address specific Agency needs, the chapters have been tailored to address program requirements. For example, some chapters (e.g., stomach cancer) provide direct medical cost information for survivors and nonsurvivors separately, while other chapters dealing with other cancers contain medical costs averaged over all patients with the disease. In each case, the approach was designed to meet the specific requirements of the Office within the Agency for whom the cost estimates were prepared. Consequently, although all chapters contain information on direct medical costs, the approaches and level of detail vary, depending on when the chapter was written and the specific requirements that the analyses were designed to address.

Many offices within EPA have funded the analyses of medical costs discussed in this handbook. These include Office of Pollution Prevention and Toxics (the primary funding office), the Indoor Environment Division within the Office of Air and Radiation, the Office of Policy Planning and Evaluation, and the Office of Water.

[2] For simplicity and brevity's sake, illnesses in the Handbook refer to diseases, birth defects, and other acute and chronic conditions requiring medical attention.

I.1.B Willingness to Pay and Cost Components

When calculating the value of human health benefits, the ideal approach would be to estimate the value of these improvements in health to everyone affected by an illness (e.g., the patient, family, friends, community). Economists measure this value in terms of how much they are willing to pay for it. Obtaining the detailed information necessary to comprehensively estimate willingness to pay (WTP), however, is complex and expensive. In addition, some components of WTP, such as the value of avoiding pain and suffering, are very difficult to estimate with accuracy. As an alternative to estimating WTP, the direct medical costs of treating diseases provides a lower-bound estimate of the benefits of reducing exposure to harmful pollutants.

I.1.B.1. Definition of Willingness to Pay

WTP is a measure of value based on the premise, central to economic theory, that the value of a good is simply what it is worth to those who consume it or benefit from it. The amount an individual is willing to pay for a particular good may be higher, or lower, than the cost of that good. WTP for a good will vary from one individual to another and may decline with how much of the good an individual already has. In the case of market goods, the comparison between the price of the good and the individual's WTP for it determines whether or not he or she buys the good. If the price is lower than his WTP, he will buy the good at less than he would have been willing to pay for it, receiving what economists call "consumer surplus." If the price exactly equals his WTP, then the individual will be equally happy whether he keeps the money and forgoes the good or pays the money and gets the good. If the price exceeds the individual's WTP, he will not buy the good.

In the context of environmental regulations and policy, economists define the value of a reduction in health risks as the sum of all individuals' WTP for it. Most people would be willing to pay something for a reduction in risk to themselves, but many people would also be willing to pay for a reduction in risk to others. Most parents, for example, would probably be willing to pay for a reduction in the risk of their children incurring a serious illness. These altruistic components of WTP may be insignificant in many cases, but they may be substantial in the case of serious diseases or disabilities. The total value of a risk reduction, then, is the sum of all WTPs for it.

Environmental contaminants generally cannot be linked with certainty to specific health effects experienced by specific individuals. Instead, the contaminants increase the *likelihood*, for all exposed individuals, of contracting specific diseases. Rather than summing the WTPs for a given

risk reduction over all those who enjoy the risk reduction, however, it is often easier to think in terms of the value of an adverse health effect avoided. Some people who would have contracted the illness will now avoid contracting it. The total value of an avoided illness is what the otherwise-afflicted individual would be willing to pay to avoid it plus what others would be willing to pay for him or her to avoid it. The sum of these WTPs is the total value of the avoided case of illness, referred to here as total WTP. In practice, average WTPs are used to value adverse health effects avoided because WTP will vary from one individual to another.

The crosswalk between valuing risk reductions and valuing a case avoided can be made by valuing a *statistical* case avoided. For example, suppose that a regulation is passed that reduces the risk of contracting pneumonia by a factor of 0.001. That means that one fewer individual out of every 1,000 people whom the regulation affects would be expected to contract pneumonia. Suppose each person has some positive WTP for this risk reduction of 0.001, and that the average WTP is $5. The total willingness to pay to avoid the one case of pneumonia that would otherwise be expected to occur per 1,000 people is $5,000 ($5 per person × 1,000 people). That is, the value of a statistical case of pneumonia avoided would be $5,000. Regulations typically affect cities of substantially greater size than 1,000 people, however, so there are typically many cases avoided. For example, if a regulation reduced the risk of contracting pneumonia by 0.001 in a city with 3 million people, there would be 3,000 (0.001 × 3,000,000) fewer cases of pneumonia expected to occur in the city as a result of the regulation. If the value of a statistical case of pneumonia avoided in that city is $5,000, the pneumonia-related benefit of the regulation in that city would be 3,000 statistical cases avoided × $5,000 per statistical case avoided = $15 million.

In theory, nonmarket goods should be valued in exactly the same way as market goods — in terms of what people would be willing to pay for them, (i.e., their willingness to pay). Unlike most market goods, many nonmarket goods are public goods, from which many people benefit simultaneously. A reduction in the risk of an adverse health effect is such a public good, because all the exposed individuals will experience a decrease in the likelihood of contracting the disease.

I.1.B.2 Components of Willingness to Pay

WTP to avoid an illness contains several components. Illness imposes both direct and indirect costs that would not be borne if the illness was avoided. Direct costs result from the increased resource utilization caused by the illness, and may be medical or non-medical. For example, the cost of an ambulance used to transport a person to the hospital is a direct medical cost, while child care and housekeeping expenses required due to illness are non-medical direct costs. In addition to the direct costs, there are

opportunity costs (the value of productive and leisure time lost) to the patient and possibly to others.[3] Finally, illness causes anxiety, pain, and suffering, the cost of which, although difficult to measure, is very real and may be very large. Most people would be willing to pay something to avoid the pain and suffering that comes with illness, as well as to see loved ones avoid pain and suffering. There is also a perceived value to most individuals of maintaining public health (i.e., most people would place some value on reducing the number of children with asthma, the number of people with cancer, the incidence of birth defects, and the occurrence of most illnesses).

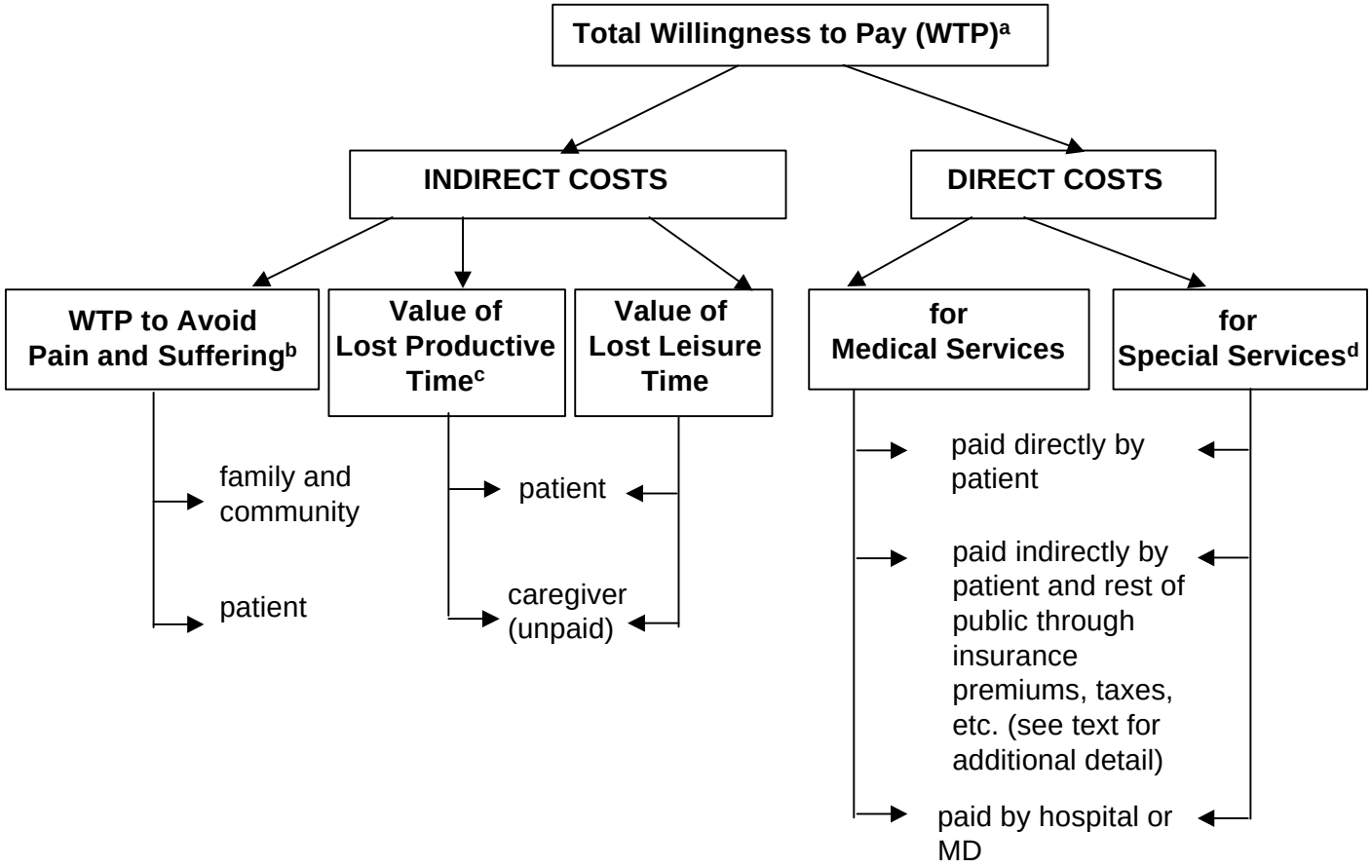
Finally, in some cases people may take precautionary actions to avoid contracting environmentally-related illnesses. People may buy bottled water, for example, if their water supply is contaminated or if they believe it may be. In these cases, there are not only costs associated with the occurrence of the illness, but costs incurred in efforts to prevent the illness. These costs would be avoided or reduced if the risk of the illness were reduced. The components of total WTP are shown in Figure I.1-1.

I.1.B.3 Approaches to Measuring Willingness to Pay

The challenge confronting the analyst is to measure the total value associated with avoiding an illness. This is a difficult challenge due to the variability in human perceptions, responses, and the complexities involved in measuring individual attitudes and extrapolating to a larger group. Economists have developed several ways to measure the value of morbidity avoided; each method has advantages and disadvantages.

[3] Opportunity cost is the cost associated with forgone opportunities. Time spent in the hospital, for example, is time that would otherwise have been spent in productive and/or leisure activities. The opportunity cost of a hospital stay is the value of the productive and/or leisure time lost during the hospital stay.

Figure I.1-1. Elements of Willingness to Pay



a. See text for a discussion of cost elements. The cost components above are associated with contracting a disease. People who avoid disease by employing averting behavior may incur other costs (e.g., the cost of buying bottled water). Both the cost components listed above, and those associated with risk avoidance would be reduced or eliminated if the risks were reduced or eliminated.

b. Heightened morbidity or other adverse effects associated with a lack of treatment (e.g., due to insufficient resources) may increase pain and suffering. This indirect cost category is very difficult to measure.

c. Lost time includes a partial or complete loss of the ability to carry out activities (paid or unpaid).

d. Includes special education (children); worker retraining (adults); workers' disability; and/or specialized equipment, transportation, and other services required due to the illness.

I.1.B.3.1 Averting Behavior.

One approach to valuing WTP relies on the averting behavior of people. This "averting behavior" approach provides estimates of WTP based on actual behavior in markets. The major drawbacks of this method, however, are that (1) it is limited to situations in which averting behavior is possible (i.e., not all contaminants can be avoided), and (2) it is difficult to isolate WTP for improved health from WTP for other aspects of the averting behavior. For example, while use of an air conditioner may reduce exposure to ambient air pollutants, it also cools the house.

Evaluation of averting behavior may be complex because pollution avoidance costs are situation dependent. Using the air conditioning example, community factors that influence air conditioner use include the extent of public notification about pollution problems, ambient temperatures, etc. Individual decision factors include a subjective rating of the pollutant's health risks.

I.1.B.3.2 Contingent Valuation

A second method, contingent valuation, is to simply ask people how much they are willing to pay for a good or service that is not traded on the market. The valuation is contingent upon establishing the market. This method involves designing surveys that present people with hypothetical situations in which they are queried about how much they would be willing to pay for a specified nonmarket good (such as to avoid a case of pneumonia). The advantage of the contingent valuation method is that it attempts to estimate the right thing — individuals' WTP. In addition, in contrast to the averting behavior approach, it can be applied to any risk reduction or adverse health effect. It is a controversial method because it of necessity elicits responses to a hypothetical situation. The reliability of the estimates obtained through contingent valuation methods is questioned by many economists and by others. The approach is resource intensive and costly. It requires careful questionnaire design and interpretation of responses. In spite of its drawbacks, it may be a useful tool for obtaining valuation data, and has the potential for contributing to a variety of planning, evaluation, and regulatory activities.

I.1.B.4 Conclusions

The cost of illness method used in this handbook estimates the direct medical costs associated with an illness. This method has several advantages. It is straightforward to implement and easy to understand. In addition, it is likely to result in relatively accurate estimates of the components of total WTP that it attempts to measure, the medical cost component. The major drawback of the cost of illness method is that it omits several components of total WTP, most notably the WTP of the patient and of others to avoid the anxiety, pain, and suffering associated with the illness. These components may be substantial, especially for

serious illnesses. In addition, this handbook does not include direct *non*-medical costs, the opportunity costs of family members or other unpaid caregivers, or time lost for the patient. Consequently, the values reported here are only a partial estimation of the cost of illness, which, as described above, is itself an underestimate of the total economic costs associated with the diseases considered. Because it omits these components, the cost of illness method provides an underestimate of WTP to avoid the disease.[4]

I.1.C Organization of Handbook.

This handbook is organized into sections based on common features of illnesses and the type of illnesses discussed, such as cancer, developmental illnesses and disabilities, diseases of specific organ systems (i.e., respiratory), and acute illnesses. They were organized in this manner because the diseases contained in these categories are similar in important aspects, including: cost calculation methods; biomedical data on disease definition, causality, susceptible subgroups, and treatment; survival patterns; and the types of medical services required and their costs. For example, cancers frequently require similar types of medical intervention, share similar characteristics regarding survival data, and have many causative agents in common. Developmental effects also share many characteristics; they manifest early in childhood, involve protracted treatment, occur in clusters, require both medical and other professional intervention, and may have similar causative agents. For both cancer and developmental effects, toxicological data are often not organ-specific, and providing general information regarding chemical associations in an introductory chapter was most appropriate. Most sections begin with a chapter that discusses the common characteristics of a disease group with respect to background medical data, cost, and causality.

[4] Some researchers (Crocker and Agee, 1995) have suggested that the cost of illness approach may not always underestimate costs (e.g., when treatments are painful and consequences are limited, patients or their caregivers may have ambivalent attitudes). If this is true, however, it is likely to be expected to be the exception rather than the norm under circumstances of fully informed medical information, because most individuals place a higher value on regaining their health (in the case of non-terminal diseases) than on avoiding medical procedures.

I.1.C.1 Illnesses Covered in the Handbook

Medical costs are provided for the following illnesses:

Cancers[5]
- breast cancer
- kidney cancer
- lung cancer
- skin cancer
- stomach cancer
- colorectal cancer
- bladder cancer

Developmental Illnesses and Disabilities
- low birth weight
- cleft lip and palette
- limb reductions
- cardiac abnormalities
- spina bifida
- cerebral palsy
- Down syndrome
- high blood lead levels

Respiratory Diseases
- asthma
- acute respiratory illnesses

Symptoms

Some of these chapters are currently in development or undergoing revisions (e.g., skin cancer).

I.1.C.2 Chapter Format

Each chapter covering a specific illness follows the same general format; the level of detail provided depends on the availability of information and the goals of the analysis. First, the chapter provides the reader with background information on the disease (Section A), including a definition and description of the disease, adverse effects related to the disease, associations with environmental pollutants, common medical approaches, and likely disease outcomes (prognosis).

The second portion of each chapter (Section B) provides specific cost information, including the methodology used to estimate costs, sources of the data, and cost estimates. Costs are provided that were current in the year in which the chapter was written or revised (1996 and forward). The

[5]Bone and liver cancer costs are also briefly discussed in the introductory cancer chapter (Chapter II.1).

Link to Chapter II.1

costs can be updated to the current year using the Consumer Price Index (CPI) Medical Services inflation data provided in "Appendix A: Inflation and Discounting Factors" on the sidebar at left.

Link to Appendix A

Section B of each chapter also discusses results and limitations of the methods used. In some cases an uncertainty and/or sensitivity analyses is also provided. Studies that provide alternative cost estimates are presented and discussed, when available. When more than one set of results is discussed, recommendations for data use are given in a section titled "Conclusions."

The headings that appear in the format of each disease chapter are listed below and described in the text that follows:

A Background
A.1 Description
A.2 Concurrent Effects
A.3 Causality & Special Susceptibilities
A.4 Treatments and Services
A.5 Prognosis

B Costs of Treatment and Services
B.1 Methodology
B.2 Results
B.3 Limitations
B.4 Other Studies
B.5 Conclusions

The chapters introducing each part of the handbook, such as cancer and developmental effects, do not follow this format because they do not deal with a specific disease.

I.1.C.3 Section Contents

The contents of each section are as follows:

A. Background:

A.1 Description: provides a clear definition of the disease and what subcategories of an illness are omitted. This section may also include data on occurrence for some diseases, depending on the needs of the sponsoring office.

A.2 Concurrent Effects: often there are other diseases associated with a given disease. These may be attributable to the same causes (e.g.,

environmental pollution). If the concurrent effects have been reported in the reviewed medical literature, then they are listed in this section. Treatment often incurs additional risk; radiation treatment, anti-cancer drugs, and other therapies can cause serious illness while curing the target disease. These secondary illnesses usually constitute a separate disease, however, so their costs are not provided in the same chapter. In some cases, the costs of these diseases are discussed in other chapters within the handbook. Concurrent effects are listed even when cost data are not provided, so that the analyst using the data can report the underestimate and uncertainty associated with additional anticipated illness.

A.3 Causality and Special Susceptibilities: information on the associations between environmental agents and diseases is presented in this category. Factors that may increase susceptibility are also discussed; these include many pre-existing conditions. Data are limited, however, on special susceptibilities. A comprehensive evaluation of illnesses that would increase susceptibility or severity of a disease was beyond the scope of this analysis. In general, a pre-existing disease in the target organ causes additional medical complications and higher costs. For example, coronary artery disease in someone with pre-existing heart disease is likely to be much more serious and costly.

1.4 Treatment and Services: includes a brief description of common treatments and related services. In most cases, this description does not include support services, such as specialized occupational training required for rehabilitation. This information was available for some the chapters that cover childhood diseases and disabilities, and so is included as supplemental cost data.

1.5 Prognosis: contains quantitative or qualitative information on likely disease outcomes. This information is important because survival probabilities, and the duration between diagnosis and death among those who do not survive, are used in cost of illness evaluations and have an impact on the cost of a disease.

B. Costs of Treatment and Services: contains medical cost data and methods used to estimate costs.

B.1 Methodology: describes methods used in calculating the costs of medical treatments and services, and the basic information used to calculate costs.

B.2 Results: summarizes cost estimates. Discounted costs at zero, three, five, and seven percent are provided for most illnesses.

B.3 Limitations: describes shortcomings of the methodology and results. These typically include a discussion of factors such as the age of the data,

sources of information, assumptions regarding treatment, and other factors that may affect the applicability or accuracy of cost estimates.

B.4 Other Studies: when other study results are available, they are presented and the advantages and disadvantages of the various studies are discussed. In all cases, the study results recommended for use are presented first and described in detail in the "Methodology" and "Results" sections. Those studies with results of limited use are presented later in this section.

B.5 Conclusions: when more than one set of results is discussed in the medical cost and/or time sections, the final recommendations regarding the optimal results are given in this section. The section is not included in chapters having only one set of study results.

I.1.C.4 Selection of Illnesses

EPA selected diseases for inclusion in this handbook based on 1) the known need for disease cost estimates for regulatory or policy activities, or 2) the anticipated need based on a review of the environmental health literature and Agency activities.

Regulations and policy evaluations often require cost and benefit information for specific illnesses anticipated to be affected by a rule or policy. Because reductions in exposure to pollutants will result in improvements in human health, evaluations of rules or policy changes may incorporate consideration of the impacts on human health, including the benefits of illness avoidance. For example, the medical cost estimates for stomach, bladder, and lung cancer provided in this handbook were developed in 1998, in response to a need for economic data for Office of Water rules covering radon and arsenic.

Illnesses were also selected based on their likely occurrence as a result of exposure to environmental pollution and anticipated future needs of the Agency for cost data. Many illnesses that are frequently associated with environmental pollutants, or that are clearly linked to pollution episodes (e.g., asthma) were evaluated and included in the handbook. For these health-based selections, the environmental health literature (i.e., toxicology and epidemiology) was consulted. The illnesses in this handbook have been linked to exposure to environmental hazards including both chemical (e.g., PCBs) and physical (e.g., radiation) hazards.

The health-based selection process included the following considerations:

- a link to environmental exposures in the toxicological and/or epidemiological literature;[6]

[6]Toxicological and epidemiological studies may strongly suggest, but rarely provide, unequivocal evidence for links between exposure and effects. Credible studies in the peer-reviewed literature that demonstrated statistically significant associations between exposure and effects were considered adequate

- illnesses that could reasonably be linked to exposure levels likely to occur in the environment;
- the availability of costing data for an illness (either in the form of multiple mergeable databases, or in the economic literature);
- occurrence linked to multiple chemicals, ubiquitous chemicals, or those of particular interest to EPA based on policy considerations (e.g., lead, mercury);
- an illness that does not result in death shortly after onset.

Professional journals were consulted for information on health effects. In addition, some federal sources, such as the Hazardous Substances Data Base (HSDB), the Integrated Risk Information System (IRIS), the Health Effects Assessment Summary Tables (HEAST), and the Agency for Toxic Substances and Disease Registry's (ATSDR) Toxicological Profiles, were used as the sources of data linking illnesses and exposure to environmental pollutants.[7] In selecting illnesses, a convergence was sought between the likelihood of an illness based on environmental exposure levels and the availability of good quality aggregate cost data from databases and research papers. For high priority illnesses, it was sometimes necessary to construct cost estimates using a theoretical approach when aggregate data were not available.

I.1.C.5 Linking Diseases to Agents

Matrices with preliminary information on environmental agents associated with cancers and with birth defects are provided in Chapters II.1 and III.1, respectively. These contain lists of hundreds of agents that have been associated with the disease categories in either toxicological or epidemiological data, or both.

Some of the agents were identified with a single disease during research on a single disease or disease category (e.g., birth defects) and have not been reviewed regarding the induction of other diseases in the Handbook. In some cases, the diseases were studied as a result of their link to an agent. For example, the costs associated with stomach cancer were evaluated for

---

evidence for inclusion in this handbook. The associations listed in this handbook are presented at the screening level; risk assessments and health evaluations require an in-depth review of the literature on each chemical.

[7] HSDB is an on-line toxicological database maintained by EPA and available through the National Library of Medicine's TOXNET. IRIS and HEAST, developed by EPA, contain data regarding carcinogenic and non-carcinogenic effects of chemicals.

a proposed radon rule. Consequently, when the stomach cancer chapter was written, an extensive search for other stomach carcinogens was not conducted.

In addition to those chemicals listed because the data were obtained for a specific chapter, data on chemicals associated with health risks were collected specifically for the matrix from general toxicological sources. Most linkages between chemicals listed and categories of effects (i.e., cancer and birth defects) did not involve an extensive search of the literature, and are often based on a quick review of relevant databases. The reader should assume that the matrices do NOT list all adverse effects of an agent, or all agents that can cause a disease. This limitation is due to the very sizable scope of the work that would be required to fully evaluate all potential effects of the hundreds of chemicals listed in the matrices. In the future additional data may be added to the matrices.

Links to Chapters II.1 and III.1

I.1.D Methods used to Estimate Direct Medical Costs

As noted above, total costs associated with an illness incorporate many elements. This handbook focuses on direct medical costs. The direct medical costs of illness are calculated for the life cycle of each illness, (i.e., from diagnosis to cure or patient death). The goal of this handbook is to provide cost estimates that are generalizable to any area of the United States; therefore, cost data representative of the nation as a whole were sought. Standard disease treatment methods, using generally acceptable practices, were also considered appropriate. Finally, the average patient experience regarding prognosis and survival was used in the cost estimate. This approach is expected to yield representative cost estimates that are generally applicable. They may be modified by changes in technology or cost structure.

I.1.D.1 Overview of Method

Six basic steps are necessary to calculate direct medical costs:

1. Identify a cohort who has received the standard treatment for the disease. If costs are to be determined by treatment component, list the standard treatment elements.

2. Determine the costs of each phase of treatment or for each treatment component and the timing of these costs.

3. Combine the cost estimates with probability data regarding the likelihood of receiving specific treatments and their timing.

Incorporate survival data in probability estimates based on the age of onset of the disease and life expectancy.

4. If total medical costs are used (rather than disease-specific cost elements), determine the background medical costs that would be incurred in the absence of the disease.[8] Modify the disease-related costs as needed to obtain incremental costs.

5. Discount the stream of treatment costs over time to estimate present value treatment costs. All costs in the handbook are adjusted to 1996 dollars using the medical care cost component of the Consumer Price Index.

6. Aggregate the discounted stream to obtain an estimate of the total medical costs of the disease.

Ideally, this process is carried out for both survivors and nonsurvivors of the disease (these two subgroups are discussed below). These basic cost estimation activities are carried out for all illnesses. As discussed above, results reported in the literature are used for many of the diseases. In a few cases, these steps were carried out specifically for the development of chapters in this handbook.

The data obtained in the various steps above are used in a single aggregating equation described by Hartunian et al. (1981) to calculate the expected direct present value costs (PVC) for any individual of a given sex, impairment category, and age at onset of impairment:

$$PVC = \sum_{n=l}^{99} \frac{P^{i}_{l,s}(n)\ DC^{i}_{l,s}(n - l + 1)}{(1 + r)^{n-l}}$$

where:

n	=	the various ages of the individual,
l	=	the age at impairment onset,
$P^{i}_{l,s}(n)$	=	the probability that a person of sex s who acquires condition i at age l will survive to age n,
$DC^{i}_{l,s}(n\text{-}l\text{+}1)$	=	the dollar value of the average annual incremental direct costs generated by such persons during year n-l+1 following impairment onset, and
r	=	the discount rate.

[8] Background costs are the average costs incurred by a population matched (e.g., in age, sex, etc.) for those with the disease, and include care for both healthy and diseased people in the population.

In reality, data rarely exist regarding the probability of survival and direct costs for a specific disease for each age of diagnosis and sex. If there were such data, however, the estimated average direct costs would be calculated by weighting the direct costs for each age and sex by the percentage of incidence in each sex/age grouping.

Appendix I.1-A, "Equations Describing the Expected Present Discounted Value of the Per Capita Lifetime Stream of Costs Associated with a Given Illness," contains a listing of equations and their input parameters used to estimate the expected present discounted value of the per capita lifetime stream of medical costs. The appendix includes more detail than is provided in this section.

Link to Appendix I.1-A.

I.1.D.2 Survivors and Nonsurvivors

Medical costs associated with a disease differ for those who survive a disease and those who die of it. For purposes of the cost analysis in this handbook, survivors are defined as those people who are diagnosed with a disease, but do not die of it (although they may die of another cause). Nonsurvivors are those who die of the disease at any point after diagnosis. Separate cost estimates for survivors and nonsurvivors are provided in the handbook for a few types of cancer, due to a specific Agency program need. These estimates are listed separately in cases where it is important to distinguish between the differing costs for the two groups, and in cases where the value of a statistical life (VSL) is used for nonsurvivors. When the VSL is used for nonsurvivors, their medical costs have already been incorporated into the cost estimate. Under these circumstances, it would be appropriate to use the medical and time (and any other costs) for survivors, but not for nonsurvivors. The use of cost data depends on the composite of all cost calculations that are being carried out for a benefits assessment.

A patient's probability of receiving specific treatments is modified by the likelihood that he or she will survive to receive that treatment. Survivors incur initial treatment costs but not charges for services, such as terminal care associated with the disease. They may die of other causes during the treatment period, and their probability of receiving treatment is modified by the probability that they will die of another cause. This probability is determined from the background mortality rates for the U.S. population, as reported by the Department of Health and Human Services publication series, *Vital Statistics in the United States* (DHHS, 1994). The probability of death due to the disease is determined from the medical literature (e.g., from the National Cancer Institute for cancers) for nonsurvivors. Determining survivorship for some illnesses, such as asthma, is very difficult due to rapid advances in treatments and the confounding effects of

limited access to care among some socioeconomic groups. When survival data are provided in a chapter, the source and confounding effects are discussed.

The methods used to calculate medical costs for survivors and nonsurvivors are described briefly below. Numerous additional calculations are often required to determine survival rates, life expectancy, etc., and are discussed in chapters where required.

I.1.D.2.1 Survivors (those who do not die of the disease)

The average cost among survivors of a disease for each year post-diagnosis may be expressed as:

Average *n*th Year Costs = medical costs for *n*th year treatment × probability of survival through the *n*th year + medical costs for *n*th year of treatment /2 × probability of mortality in the *n*th year

As this description indicates, the costs decline as the population decreases due to mortality. Costs are discounted back to the year of diagnosis. Costs for those who die are calculated for one half year because they are assumed to die at the midpoint of the year. Their survival rate is equal to the background mortality rate at each age in the U.S. population as reported in vital statistics reports (e.g., *Vital Statistics of the United States*, DHHS, 1994).

The yearly costs are aggregated over the remaining life of the "average" patient. For example, if the average age of a patient is 40 and medical visits and drug treatment for asthma are anticipated to be required over the expected lifetime for a 40-year-old in the general population, the costs for each year are calculated, discounted from the time of diagnosis, and summed over a lifetime. This generates a lifetime stream of costs.

Average Lifetime cost = Average 1st year cost + the sum of the (discounted) average subsequent year costs

If there is a point at which treatment ceases (e.g., ten years after diagnosis and treatment for cancer), the costs will be aggregated over time up to that point. When this approach is compared to the equation supplied by Hartunian et al. (1981) shown in section I.1.D.1, it can be seen that the overall cost estimation method is the same.

Link to Section I.1.D.1

I.1.D.2.2 Nonsurvivors (those who die of the disease)

The method for calculating medical costs for nonsurvivors is similar to that shown above for survivors, but the costs themselves are often different, and the probabilities used to calculate costs differ. For nonsurvivors, the

probability of treatment is contingent on surviving the study disease for each year after disease onset. The general descriptions are the same as those shown above.

I.1.D.2.3 Average Costs for Survivors and Nonsurvivors

The average lifetime medical costs of a disease are estimated for survivors and for nonsurvivors separately. The average cost for both together is calculated as a weighted average of costs for the two groups, using the proportion of patients in each group. This can be expressed as:

Average Lifetime medical costs = costs for survivors × proportion of survivors + lifetime costs for nonsurvivors × proportion of nonsurvivors

I.1.D.3 Data Sources

Most cost estimates provided in this Handbook rely on an evaluation of databases of actual costs incurred, either for this Handbook or by previous researchers. Each chapter describes how various data sources were used to calculate the final results, and contains a discussion of uncertainties associated with data sources.

Well-designed studies in the literature that supplied recent cost estimates were located for most illnesses and were preferred over data collection and evaluation for the sake of efficiency. For example, many of the childhood disease chapters in this handbook are based on work done by Waitzman et al. This research group used 12 databases to accurately construct their cost estimates.

Link to Chapter II.2

Using the results of these studies is more efficient than constructing costs directly from multiple databases. Extensive resources are required to evaluate national databases, and confidentiality is often an issue that requires a lengthy timetable for clearances. Most chapters use a combination of data obtained from the literature and directly from data sources. Results reported in the literature are supplemented by survival or other essential data to obtain cost estimates.[9]

[9] For example, Baker et al. (1989 and 1991) were used as a source of basic cost information for many of the cancer chapters. Additional data required for the cost analyses regarding survival and mortality estimates and cancer rates were obtained directly from the National Cancer Institute's databases. These combined sources were used to calculate cost estimates.

Cost estimates were developed for some diseases by constructing a typical treatment course through physician panels, and evaluating the cost of each treatment component using sources such as the Medicare database. This approach relies on expert judgment by physicians who determine treatments that the average patient receives, the timing of treatments, and the likelihood that a percentage of patients will receive a particular treatment. Survival data are obtained from a secondary source.

Limitations to this approach include physician errors in recall, physician experience with a non-representative population, and incomplete knowledge of variations in treatment patterns geographically and among physician specialties. In addition, the approach tends to estimate ideal costs because physician panels describe the treatment and costs that a person with a disease *should* receive, whereas the direct cost estimation approach described above is based upon actual costs. For example, skin cancer costs were evaluated using physician recommendations. The protocol described is one that provides the most appropriate care; it is not necessarily the most expensive, but assumes that everyone receives the services that would address their medical needs adequately. In practice this does not happen, due to a variety of factors (e.g., limited access or funds, avoidance of diagnosis).

Consequently, the chapters based on physician recommendations for treatment describe costs associated with sound medical practice, and these values may be higher than the "average" for the U.S. Adequate care for all patients probably reduces time loss, however, so that what is theoretically spent on complete medical care may be balanced by related reductions in unnecessary morbidity and mortality. When these types of analyses have been done, they generally find that preventive and/or adequate medical care costs are more than offset by reductions in future morbidity, time loss, and special services required (e.g., special education).

Due to the limitations of the approach and the resources required to carry out an analysis based on this type of cost evaluation, it was used for very few chapters in this handbook.

I. 1.E Susceptible Subpopulations

Many diseases affect subgroups of the population disproportionately. The subgroups may be defined by age, gender, racial, ethnic, socioeconomic, or other differences within the U.S. population. For example, asthma is most often reported and treated in children and the elderly. Most cancers occur with increasing frequency in older populations (some leukemias being notable exceptions). Very few diseases affect all population groups (ages, sexes, races) equally. For purposes of evaluating costs and potential benefits to different segments of the population, it is useful to evaluate

whether there are susceptible subpopulations that require consideration. Their benefits may be considerably higher than those of the average member of the general population.

Each chapter contains a section titled "Causality and Special Susceptibilities" that contains information gathered to address this issue. An exhaustive search was not carried out for these data, however, and new information is being generated rapidly in this field. Consequently, there may be susceptible subgroups not identified in this section. In addition, there are usually pre-existing medical conditions that will increase susceptibility to most diseases (as noted previously), such as a pre-existing disease in the same organ.

Special susceptibilities are often indicated by higher-than-average rates of the disease of interest. Increases in the rates of reported diseases may be due to a variety of factors. Some of these indicate an increased susceptibility; others are matters of personal choice and may not be considered relevant to cost calculations. One way to approach this issue is to evaluate increased susceptibility when it is based on an increased risk of disease due to factors *reasonably beyond the control of the subpopulation*. Factors that are usually beyond the control of the individual that may cause increased susceptibility include:

- constitutional limitations (e.g., illnesses, genetic abnormalities, birth defects such as enzyme deficiencies);

- concurrent synergistic exposures that cannot reasonably be controlled (e.g., at home or in the workplace);

- normal constitutional differences (i.e., differences based on sex, age, race, ethnicity, etc).

Other factors that are not usually considered beyond the individual's control include personal choices, such as smoking, drinking, and drug use. These factors may be included in an analysis depending on the goals of the analysis. Which types of factors should be included in an analysis is a policy decision. Personal choice typically does not include the place of residence or work, since these are not reasonably changed by many people. For example, asthmatic smokers who increase their risk of asthma are not discussed at length as susceptible subpopulations; however, asthmatic residents of an area with high levels of acid aerosols may require additional analysis of their risk of asthma and benefits of asthma avoidance. It may be useful to evaluate the medical costs of people in the latter group using different underlying risk factors than would be appropriate for the overall U.S. population.

These types of considerations are not used directly in the cost calculations presented in this handbook. Much of the information regarding special susceptibilities is incorporated, however, into the medical information provided in the background sections of each chapter. In addition, sensitivity analyses in some chapters include an analysis of the impact on subgroups at highest risk.[10] The data may be used in a variety of ways, depending on the nature of the benefits assessment.

The degree to which special susceptibilities should be considered in an assessment depends on the extent of impact that is expected in the cost analysis (e.g., whether the differences will be substantial or minimal), as well as equity considerations. For example, the rate of stomach cancer in African-Americans is much greater than in non-African-Americans. There is no conclusive information regarding the cause of this increase, so it is assumed that it may be due to a genetically determined increase in susceptibility to stomach cancer. Because these differences are consistent across the ages, there is no modification required in the *per capita* cost estimates for stomach cancer. If an area that was predominantly African-American was the subject of a benefits assessment, however, the increased risk in that area would merit consideration in the benefits assessment. If risk factors for the general population were used with the per capita costs, then the impact on the area would be estimated incorrectly. Most chapters contain some information regarding known increases in susceptibility. Some have considerable detail, such as the chapter on stomach cancer (Chapter II.2) where basic information on differences in stomach cancer rates based on race and sex from the National Cancer Institute are provided. These data could be used by risk assessors or epidemiologists to evaluate the potential for increased risk.[11] Their results, together with the economic data, could then be used in a benefits assessment. This same approach may be used for any diseases for which a susceptible subgroup of interest has been identified.

Link to Section I.1.B
Link to Chapter II.2

[10] This type of analysis was begun in 1998 in response to specific needs regarding high-risk subgroups. It is not contained in earlier chapters, but may be added in the future.

[11] This type of analysis is complex because it requires an evaluation of the proportion of cases expected in the population subgroup as well as in the overall population. This requires calculation of the conditional probabilities of stomach cancer based on race. Because the overall stomach cancer rates incorporate the rates for both blacks and non-blacks, the likelihood of occurrence in each of these two groups would need to be determined. This information would be used with the racial distribution in the target population to determine the estimated potential risk.

I.1.F Limitations

The limitations of the data provided in this handbook are related to two primary constraints:

1) the scope of the analysis, and

2) uncertainty regarding the data used in the analysis.

The scope of the analysis, described in the introduction to this chapter, includes only direct medical costs. Many aspects of the willingness to pay to avoid these illnesses are not covered in the handbook, including direct non-medical costs and pain and suffering (see discussion in Section I.1.B and Figure I.1-1).

Link to Figure I.1-1

There are numerous sources of uncertainty associated with the values presented in this handbook. The background and cost sections of the chapters provide definitions and information on the "average" medical experience and costs for a disease. Outside this experience, however, numerous factors impact the costs associated with specific diseases and lead to uncertainty in the cost estimates. The sources of uncertainty specific to each disease cost analysis (i.e., the databases used in an analysis, the methods of the analysis) are discussed in the individual disease chapters. Those common to all diseases are discussed in this section.

I.1.F.1 Uncertainties Regarding the Market Value of Medical Goods and Services

As noted above, direct medical costs are provided in this handbook as a component of WTP and may be used as a lower estimate of WTP. For a variety of reasons, however, the price of medical services and the mix of services purchased may not accurately reflect the market demand and value for these services. These reasons are related to the nature of what is purchased when buying medical services, and the way in which medical services are paid for in the U.S.

I.1.F.1.1 The Nature of Medical Service Purchases

The nature of what is being purchased is often unclear when obtaining medical services. Although a specific service or good is usually being obtained at a point in time (e.g., surgery, a pharmaceutical, an X-ray), the ultimate goal of the purchase is invariably an improvement in health. The latter, often purchased through multiple related services and goods, is generally far more valuable to the individual than the individual service or item. For example, when faced with a serious illness, individuals would

expend the maximum funds they have available to avoid death or permanent disability.[12]

Just as individuals may be willing to bear almost any medical costs required for serious illnesses, society is often willing to spend very large sums to avoid illness or death among otherwise healthy individuals. Extensive and expensive health programs for indigent populations illustrate the interest in the overall health of the population. This may be both the provision of a public good and a self-protective strategy. Likewise, societies are often willing pay very large medical costs under special circumstances. For example, communities have raised millions of dollars to provide cancer treatments for a relatively small number of children. What a society or individual would be willing to pay for medical services may be strongly affected by a society's response to potentially drastic consequences. The willingness to pay very large medical costs to avoid dire consequences is expressed both by the individual with the illness and by those who are aware of the individual's plight.[13]

There is an interactive relationship between what medical costs society is willing to pay and standard medical practice (which dictates costs), which often reflects societal values. This dynamic may further diminish individual control over the purchase of medical services and their impact on the market for medical services. When insurance companies, the government, or medical practice standards determine access to care or determine what constitutes appropriate treatment, individual choice may be limited; this may also affect cost. For example, both the costs of treating a disease such as breast cancer and access to care for that disease may be quite different for patients of different ages or with different health status (i.e., AIDS vs good health).

I.1.F.1.2 The Sources of Payment for Medical Services

A second major source of possible inequality between medical costs and market values is the system of medical payments in the U.S. The system creates institutional reasons for a disjunction between costs, payments, and WTP for both individuals and society. As Figure I.1-1 shows, there are often a multitude of sources of payment for medical costs. In the case of medical services, people have typically prepaid insurance premiums or taxes (e.g., for Medicare and Medicaid) that are used as the source of payment. This prepayment may affect the demand for and the costs of

[12] This discussion generally addresses people who prefer a cure over death. Although the latter may occur, it is not the norm and is not directly relevant to determining willingness to pay for services to improve health.

[13] Alternatively, there is often opposition to high medical costs associated with prolonging life for the very elderly, terminally ill, or those with certain types of health problems.

services at the time the service is rendered, since the funds have already been expended.

Link to Figure I.1-1

In addition, prepaid premiums or taxes are not designated for specific services, but are held to be distributed on an as-needed basis (with need being controversial in some cases). Consequently, insurance payments are not provided equally to all premium holders due to differences in medical services required. Thus, the premium holders have purchased an assurance that their medical bills (or some portion of them) will be paid rather than paying for a specific service. This is quite different than payment for a specific treatment at the time it is needed based on decisions regarding its value to the individual. There is no direct connection between payment for and receipt of a good or service.[14]

When costs are high and exceed the amount of the premium (or individual taxes), the excess is borne by a group rather than by the patient. This system of payment also reinforces the concept that when the general public purchases insurance or approves funding for public health programs, it is buying some assurance of good health rather than specific services. Patients may be willing to pay more for an improvement in health status than for a specific service.

For some individuals and groups, the payment system is quite complex, and determination of the costs of medical services and WTP is even more difficult. For example, elderly patients, who comprise the majority of those who suffer from cancer, chronic obstructive pulmonary diseases, heart disease, and many other illnesses covered in this handbook, often have multiple sources of payment, including Medicare (for which they often pay premiums and taxes), private insurance, free clinic care for some services (paid for by local funds), and direct out-of-pocket expenditures.

I.1.F.1.3 Conclusions Regarding the Market Value

These factors distort the simple connection between the price paid and the actual costs that exists for purchasing many other goods and services. Under these circumstances, it is difficult to determine precisely what an average patient would be willing to pay. Although such uncertainties may lead to an over- or underestimate of WTP, the illnesses in this handbook are very serious in nature (i.e., either life-threatening or capable of resulting in very debilitating conditions), and people are likely to be willing to pay much more than they currently pay out-of-pocket or indirectly (e.g., through insurance premiums). The value to the afflicted individual and/or friends and family of avoiding the anxiety, pain, and suffering associated

[14] As Figure I.1-1 shows, there are some direct payments of medical services by the patient; however, full payment for major illnesses by a patient is relatively uncommon.

with the illness (see Figure I.1-1) may be considerably greater than those cost components included in the cost-of-illness approach.

Link to Figure I.1-1

Because the payment of medical costs comes from multiple sources, both direct and indirect, the purchase of medical services is actually determined by multiple and diverse groups. Those who have a role in determining medical costs and standard services for illnesses include insurance premium payers; taxpayers and their elected representatives (who are involved in determining payments for publicly funded services); state, local, and national agencies, whose staff are also publicly accountable; corporations with stockholders; medical personnel; and others. The overall cost of living, employment characteristics, and cost for durable goods also play a role. Consequently, although there are disjunctions and complications in the determination of medical costs, the diversity of decision-makers in the cost-setting process provide some assurance that medical costs reflect the preferences of society.

I.1.F.2 Differences in Critical Patient Characteristics.

Some factors are related to individual characteristics. They introduce uncertainty into the use of cost only if the population of concern (e.g., the study population for a benefits assessment) has characteristics that differ from those of the "average" members of the population with the disease. These factors include:

- the organ systems affected by the disease (e.g., which systems, multiple versus single systems);
- the severity of the disease (may be related to the above);
- the general health of the patients aside from the disease in question;
- other complicating medical conditions in the patients; and
- the life expectancy of the patients (this affects the length of treatment)

I.1.F.3 Geographic Differences in Medical Practices and Services

Other factors that impact costs are associated with medical practices and services in a geographic area. These factors may differ substantially among various areas of the U.S. For example, urban areas generally have higher direct medical costs than rural areas.

Factors of concern regarding differences in medical practices and services include:

- the specific treatment protocols chosen;
- the hospital and professional fee rate structure in a particular area; and
- the support systems that provide care at no cost (e.g., home care).

Access to care is a particularly difficult factor in evaluating medical costs and has a complex role in their calculation. Consequently, is it usually discussed only qualitatively as a source of uncertainty. Its actual cost impacts are rarely known. Access to services varies on a geographic and socioeconomic basis and often increases both risks and costs for economically disadvantaged patients. For example, access to medical care has been found to be a critical factor in survival among people with asthma, with limited access to care being closely linked to poverty status in some major cities.

Access to care has multiple components. It includes the physical availability of services. A one-hour bus trip to a clinic may be a major impediment to care, and be replaced by the use of ambulance transport to an emergency room rather than a doctor's office because an "emergency" is required to obtain transportation (given that the bus ride is not a reasonable option for someone who is sick). Moderately ill people who could be seen in a clinic may be seen in a much more expensive emergency room due to lack of access to designated Medicare/Medicaid clinics.

A second, and often more costly impact of limited access to care, is the condition of the patient when he or she receives services. Access issues may lead to delays in obtaining care so that disease management is poorer. This care differential impacts the outcome and often leads to higher mortality (as mentioned above with respect to asthma). The overall costs of this factor, in direct and indirect costs (including pain and suffering), is substantial. The vast majority of deaths from asthma occur among children and the elderly who are below the poverty line.

When evaluating benefits, some aspects of the impacts of access to care and other problems related to socioeconomic status may be relevant, especially for chronic low-level diseases (e.g., COPD, asthma, cardiovascular diseases). They are also relevant to cancers in which the late diagnosis, in part due to less frequent medical checkups, is often noted as a contributing factor to the higher mortality rate among lower socioeconomic groups. An example is the strong positive association between the probability of mammograms and family income. The reduced use of this diagnostic tool among poorer women is linked to their increased

risk of breast cancer being diagnosed at later stages of the disease. This delay leads to a poorer overall survival, higher medical costs, and increases in lost time.

As noted previously, differences in medical practices and services will be relevant ONLY if a benefits analysis focuses on an area or population subgroup within the U.S. where the practices and services differ from the "average" in the U.S. Most cost estimates in the handbook are derived from databases that cover a wide socioeconomic and geographic spectrum.

I.1.F.4 Uncertainty Regarding the Application And/or Accuracy of Input Data

Varied data sources are used for most cost analyses. These sources range from scientific papers reported in the medical economics literature to census and National Cancer Institute (NCI) data regarding demographics and background rates of mortality, cancer diagnosis, and patient survival. The quality and applicability of the input data are relevant to all uses of the cost data. Uncertainty regarding the inputs to the cost estimates fall into the following categories:

- accuracy of estimates from primary sources,
- accuracy of "background" cost estimates used with the disease cost estimates to calculate the incremental costs,
- accuracy of life expectancy estimates for patients who are either survivors or nonsurvivors of the disease,
- accuracy of estimates of the percent of survivors and nonsurvivors,
- accuracy of the estimates of survival among people without the disease (used for background calculations),

I.1.F.4.1 Geographically Representative Data

As noted previously, national data were sought to obtain the best "average" estimate for each input parameter. Estimates were usually obtained through the use of data on a cross-section of people with a similar mix of ages, sexes, races, etc., to that of the overall U.S. population. Often a subset of a national database was used, or the entire database for specific years was obtained. This national approach provides a reasonably good estimate of costs. As always with sampling, there is a small chance that the data selected will not be entirely representative, thereby introducing some uncertainty. This is not likely, however, to be a major source of uncertainty.

Some diseases were evaluated based on data from a specific geographic area. For example, some chapters on birth defects (e.g., cleft lip and

palate) were obtained from a detailed analysis conducted by Waitzman et al. (1996) that used 18 databases in California to obtain a complex and comprehensive description of direct and some indirect costs of the disorders. California is economically and demographically diverse, and so, as noted in the chapter, it is believed that the cost estimates are reasonable approximations of a national average. Still, the use of location- or population-specific data introduces additional uncertainty. When data were used that generate this type of uncertainty, relevant concerns are described in the chapter.

I.1.F.4.2 Treatment Estimates

As discussed previously, a few chapters rely on treatment protocols provided by physicians to estimate medical costs. These protocols cause uncertainty in estimating medical costs, due to the assumption that all patients receive timely and adequate medical care, which is not always the case in practice. Some patients don't seek care, some delay treatment, and others are treated for only a short time. These behaviors are due to a variety of factors. Evaluating the impact of this approach on costs is difficult because a delay in care, while reducing immediate costs, usually leads to increased costs in treating a more severe form of the disease and a longer disability period, or in early mortality and an associated increase in lost time. Rather than determining the direction of impact on costs (higher or lower), it is simply noted that the cost estimate based on a physician protocol introduces additional uncertainty.

I.1.F.4.3 Conversions and Calculations

Other types of uncertainty are introduced by the use of data that are relevant, but not expressed in the units required for this analysis. Agencies and researchers typically provide data in a format that is most useful for their goals; this often does not match the requirements for cost estimation. Consequently, the raw data obtained often require additional modifications using inputs from multiple sources. For example, survival among cancer patients is expressed as a relative survival rate (RSR) in the NCI databases. It was necessary to convert the relative survival rate to an absolute survival rate to carry out essential cost calculations. RSRs incorporate a background mortality rate from the general population, as well as other inputs, in their derivation. Various sources were consulted for the inputs (e.g., the U.S. Census Bureau, mortality probabilities from NCI) and the absolute survival rate was calculated. This type of calculation, which is a derivation of a critical value, introduces uncertainty regarding the result. The outcome is not likely to have substantial error, but there is not the certainty that would be obtained if the absolute rates were available from a primary source.

I.1.F.4.4 Changes in Medical Services Provision and Medical Costs

The most common source of uncertainty is introduced by the use of data that are not "current." There is no single definition of "current" because the relevant concern is whether the cost estimates reflect ongoing practices and costs. Medical approaches for some diseases have changed considerably in recent years, while others remain very similar for many years. Services and costs reflect changes and improvements in the technical aspects of how medical care is delivered.

In addition to technical changes in how medicine is practiced, there have been numerous changes in the way medical services are provided and in medical costs during the 1980s and 1990s. Medical cost containment is a relatively recent focus of private sector payers (e.g., insurance companies, managed care providers) and has been the subject of considerable effort at the federal level since the outset of the Medicare and Medicaid programs. The rapidly escalating medical costs of the 1970s and 1980s led to a national recognition of the need for medical cost containment. New systems of care management and payment have evolved in recent years and continue to evolve. Consequently, it is difficult to compare current costs directly with those of the past. This is relevant to the costs presented in the Handbook because many of the cost estimates are based on data collected in past years.

Changes in payment structures and cost containment efforts proceeded hand-in-hand with changes in the way in which services are provided. In many cases, cost containment is partially accomplished through limitations on the types of services or the specialty of the physicians to which a patient has access. Thus, cost control efforts have been directed both at slowing the increase in cost for a specific service, and in limiting the access to expensive services. The consumer price index (CPI) medical care component is used in the Handbook to inflate costs obtained in past years to the most recent year available. The CPI was designed to estimate the increases in costs associated with a specific service or item. It does not address the issue of access to services. Although there have been studies of the impacts of access limitation and other cost containment strategies, there is not a single agreed-upon value that can be applied to compare either services for a specific disease, or costs for that disease over time, independent of factors other than access limitation.

Wicker et al (1999) contains a discussion of cost containment programs' impact on patterns of care and the readmission of patients with respect to children. They discussed utilization management (UM), which provides for review and authorization of both inpatient and outpatient care for more than 90 percent of enrollees in group insurance plans (HMOs, preferred provide organizations, etc). Their study pointed out an ongoing problem related to this cost reduction strategy: by limiting care through the review

process, UM decreases initial inpatient costs but increases the rate of hospital readmission. This was noted in particular for low birth weight infants and those with depression or drug or alcohol dependence problems (Wicker et al., 1999). These are very common chronic conditions among children and adolescents, and are also among the more costly conditions due to their chronic nature. Consequently, the dynamic observed for these conditions is potentially relevant to most chronic conditions. A similar dynamic has been observed in adult patients, for whom delays in referrals to specialists and specialized treatment led to more serious illnesses requiring more costly care than would have originally been required. In the most extreme cases, denial of services had led to death (and subsequent court settlements).

What Wicker et al. and other studies suggest is that cost reductions using resource limitation strategies may not reduce costs overall, at least in some cases. In addition, the application of UM and other similar strategies varies greatly in implementation, and its application is not universal. Making simple assessments the impacts of trends in medical services, management, and costs on the overall lifetime costs of an illness is therefore difficult. The Handbook attempts to clearly state both the source of cost data and limitations in the methods of data collection, study design, and other factors that may affect how the cost data can be applied currently. It is often not known if the costs for an illness are over- or underestimates of current costs. Where new treatments are known to be offered and their likely cost impact is known, however, that information is provided (usually qualitatively).

When evaluating changes over time in costs and services, it is important to consider all inputs to cost. For example, when the data on breast cancer costs were collected, bone marrow transplants were not yet being done. Now they are offered for the most advanced cases of the disease and they are very expensive. Because they are provided to a small percentage of women with the disease, they will not have a substantial impact on the overall costs; however, bone marrow transplants may slightly increase the average cost of treatment. Balancing this is the fact that women receiving this treatment are less likely to die. Consequently, any application of mortality percentages and the value of statistical life (VSL) to breast cancer patients may overestimate the mortality-associated costs. In addition, there is some evidence that women are being diagnosed with breast cancer at earlier stages, which decreases the risk of death but also increases the direct medical costs because they are living longer and requiring additional services. Given the difficulty in evaluating changes in services and costs over time, and the extreme difficulty in obtaining a national average lifetime medical cost for most diseases, the cost estimates provided in this Handbook offer a reasonable approximation, with the limitations associated with the estimates acknowledged.

Appendix I.1-A Equations Describing the Expected Present Discounted Value of the Per Capita Lifetime Stream of Costs Associated with a Given Illness

Illnesses are costly in many ways and often over long periods of time.[15] Many illnesses result in costs for years after onset; some illnesses result in a lifetime of costs. Some of these costs, such as hospitalization charges and physician fees, are obvious. Other costs, such as the value of lost time due to the illness, are less obvious but just as real. A complete accounting of the total cost of an illness includes *all* the costs incurred as a result of the illness from the time of onset to the time of cure or the death of the individual — that is, the lifetime stream of costs associated with the illness.[16]

Properly estimating the total value of this lifetime stream of costs requires understanding several key considerations, including:

- costs incurred at a later time should be discounted,
- there are several different kinds of cost, and
- the costs of an illness are incremental costs.

The lifetime stream of costs associated with an illness will vary from one individual to another for a variety of reasons, including, for example, the age of onset of the illness. For each year post-diagnosis, moreover, direct costs can be incurred during that year only if the individual survives to that year.[17] If the individual dies in that year, then indirect costs are incurred. The number of years of survival post-diagnosis, however, will also vary from one individual to another. A fourth consideration, then, is that:

- it is not "a lifetime stream of costs" that is of interest, but rather the *expected*, or average, lifetime stream of costs.

To estimate this average value, it is necessary to know the probabilities of survival for each year post-diagnosis.

---

[15] Birth defects are included within "illnesses."

[16] Even a complete accounting of all costs of an illness will yield an underestimate of the true social value of avoiding the illness, because it does not take into account the value of avoiding the pain and suffering associated with the illness.

[17] Estimates of the costs of an illness are usually used as lower-bound estimates of morbidity costs rather than as estimates of the value of avoiding premature mortality from the illness. Estimates of the value of avoiding premature mortality are generally substantially higher than cost of illness estimates.

The expected present discounted value of per capita lifetime incremental costs of an illness can be constructed from its component parts. Each of the expressions or parameters used in this construction is explained in the table below. When an expression is derived from other expressions and/or parameters, the derivation is given in the table. All costs are average per capita costs and are incremental (i.e., the costs of the illness beyond those expected to be incurred by the same individual in the absence of the illness).

Table I.1.A-1: Estimation of the Expected Present Discounted Value of Per Capita Lifetime Incremental Costs of an Illness		
Parameter		**Derivation**
The cost of heightened morbidity:		
j	number of years post-diagnosis (an index)	
$dc_j^{medical}$	direct medical costs j years post-diagnosis	
$dc_j^{nonmedical}$	direct nonmedical costs j years post-diagnosis	
ic_j^{vlphm}	indirect costs j years post-diagnosis: value of lost time due to heightened morbidity, estimated as the number of units of productive time (e.g., hours or days) lost in the jth year post-diagnosis due to the illness times the value per unit time.	
ic_j^{vllthm}	indirect costs j years post-diagnosis: value of lost leisure time due to heightened morbidity, estimated as the number of units of leisure time (e.g., hours or days) lost in the jth year post-diagnosis due to the illness times the value per unit time.	
$cost_j^{hm}$	total costs of heightened morbidity incurred j years post-diagnosis. $Cost_j^{hm}$ is an *average* cost among all those with the illness who survive j years post-diagnosis. Any of the components of $cost_j^{hm}$ may vary from one individual to another because of factors such as sex or age.	$cost_j^{hm} = dc_j^{medical} + dc_j^{nonmedical} + ic_j^{vlphm} + ic_j^{vllthm}$
The cost of premature mortality:		
r	discount rate, reflecting individuals' positive rate of time preference.	
x	age of onset of the illness	
d	age of death from the illness	If death from the illness occurs j years post-diagnosis, d=x+j.
m	expected age of death, in the absence of the illness	

Table I.1.A-1: Estimation of the Expected Present Discounted Value of Per Capita Lifetime Incremental Costs of an Illness		
Parameter		**Derivation**
vp_k	value of time at age k (in the absence of the illness), estimated as the number of units of time (e.g., days or hours) of time at age k times the value per unit time.	
vlt_k	value of leisure time at age k (in the absence of the illness), estimated as the number of units of leisure time (e.g., days or hours) at age k times the value per unit time.	
ic^{vlppm}	indirect costs: value of lost time due to premature mortality. This is the sum of discounted values of time for each year that the individual would be expected to live in the absence of the illness but did not live — i.e., from the age at death (d) to the expected age at death (m).	$$ic^{vlppm} = \sum_{k=d}^{m} \frac{vp_k}{(1+r)^{k-d}}$$
ic^{vlltpm}	indirect costs: value of lost leisure time due to premature mortality. This is the sum of discounted values of leisure time for each year that the individual would be expected to live in the absence of the illness but did not live — i.e., from the age at death (d) to the expected age at death (m).	$$ic^{vlltpm} = \sum_{k=d}^{m} \frac{vlt_k}{(1+r)^{k-d}}$$
$cost_j^{pm}$	total costs of premature mortality for an individual who dies j years post-diagnosis. $Cost_j^{pm}$ is an *average* cost among all those who die from the illness j years post-diagnosis. Any of the components of $cost_j^{pm}$ may vary from one individual to another because of factors such as sex or age. As noted above, if death from the illness occurs j years post-diagnosis, then age at death is d=x+j. Medical costs included in $cost_j^{pm}$ are those medical costs that would not have been incurred in the absence of death from the illness (e.g., terminal care costs of cancer).	$$cost_j^{pm} = dc_j^{medical} + ic_j^{vlppm} + ic_j^{vlltpm}$$ where $$ic_j^{vlppm} = \sum_{k=d}^{m} \frac{vp_k}{(1+r)^{k-d}}, \quad d = x+j$$ and similarly for ic_j^{vlltpm}

Table I.1.A-1: Estimation of the Expected Present Discounted Value of Per Capita Lifetime Incremental Costs of an Illness		
Parameter		**Derivation**
Expected costs:		
ps_j	probability of surviving j years post-diagnosis	
pd_j	probability of dying j years post-diagnosis	$pd_j = ps_{j-1} * (1 - ps_j)$
$E(cost_j)$	expected costs incurred j years post-diagnosis. This is the *average* cost of the illness j years post-diagnosis — the average cost of heightened morbidity times the probability of surviving j years post-diagnosis plus the average cost of premature mortality times the probability of dying j years post-diagnosis.	$E(cost_j) = ps_j * cost_j^{hm} + pd_j * cost_j^{pm}$
Age-of-onset-dependent costs: *The costs and probabilities of surviving or dying j years post-diagnosis may depend not only on j but on the age of onset of the illness, or, equivalently, on the individual's age (x+j) j years post-diagnosis. The probability of someone who gets lung cancer at age 45 surviving to age 46, for example, may be very different from the probability of someone who gets lung cancer at age 70 surviving to age 71. The above parameters are therefore further refined below.*		
$cost_{j,x}^{hm}$	total costs of heightened morbidity incurred j years post-diagnosis, given that age of onset is x. This is a refinement of $cost_j^{hm}$ which acknowledges that one or more components of the costs of heightened morbidity may depend not only on the number of years post-diagnosis but also on the age of onset or, equivalently, on current age (x+j).	$cost_{j,x}^{hm} = dc_{j,x}^{medical} + dc_{j,x}^{nonmedical} + ic_{j,x}^{vlphm} + ic_{j,x}^{vllthm}$
$cost_{j,x}^{pm}$	total costs of premature mortality for an individual who dies j years post-diagnosis, given that age of onset is x. This is a refinement of $cost_j^{pm}$ which acknowledges that the components of the costs of premature mortality may depend not only on the number of years post-diagnosis but also on the age of onset, or, equivalently, on current age (x+j).	$cost_{j,x}^{pm} = dc_{j,x}^{medical} + ic_{j,x}^{vlppm} + ic_{j,x}^{vlltpm}$

Table I.1.A-1: Estimation of the Expected Present Discounted Value of Per Capita Lifetime Incremental Costs of an Illness		
Parameter		**Derivation**
$ps_{j,x}$	probability of surviving j years post-diagnosis, given that age of onset is x.	
$pd_{j,x}$	probability of dying j years post-diagnosis, given that age of onset is x.	$pd_{j,x} = ps_{j-1,x} * (1 - ps_{j,x})$
$E(cost_{j,x})$	expected total costs incurred j years post-diagnosis, given that age of onset is x.	$E(cost_{j,x}) = ps_{j,x} * cost_{j,x}^{hm} + pd_{j,x} * cost_{j,x}^{pm}$
Discounted expected costs: *Expected costs incurred j years post-diagnosis are discounted back to the time of diagnosis (onset) of the illness.*		
$PDVEC_{j,x}$	present discounted value of expected costs incurred j years post-diagnosis, given age of onset x.	$PDVEC_{j,x} = \frac{E(cost_{j,x})}{(1+r)^j}$
$PDVEC_x$	present discounted value of the *lifetime stream* of expected costs when age of onset is x. This is the sum of discounted expected costs from onset of the illness at age x until either cure or the death of the individual.	$PDVEC_x = \sum_{j=0} PDVEC_{j,x} = \sum_{j=0} \frac{E(cost_{j,x})}{(1+r)^j}$
p_x	probability that the age of onset of the illness is x	

Table I.1.A-1: Estimation of the Expected Present Discounted Value of Per Capita Lifetime Incremental Costs of an Illness		
Parameter		**Derivation**
EPDVEC	*expected* present discounted value of lifetime costs, i.e., the average over all possible ages of onset.	$EPDVEC = \sum_{x=0} p_x PDVEC_x = \sum_{x=0} p_x \sum_{j=0} \frac{E(cost_{j,x})}{(1+r)^j}$
Approximations or alternatives to EPDVEC:		
av	the average age of onset of the illness	
$PDVEC_{av}$	present discounted value of the *lifetime stream* of expected costs when age of onset is the average age of onset. $PDVEC_{av}$ is $PDVEC_x$, where age of onset is the average age of onset; av. $PDVEC_{av}$ is an approximation to EPDVEC.	$PDVEC_{av} = \sum_{j=0} PDVEC_{j,av} = \sum_{j=0} \frac{E(cost_{j,av})}{(1+r)^j}$
n	average number of years post-diagnosis at which cure or death occurs	
$PDVC_{avg}{}^{hm}$	present discounted value of the lifetime stream of costs of heightened morbidity associated with the illness for the "average individual" diagnosed with the illness.	$PDVC_{avg}{}^{hm} = \sum_{j=0}^{n-1} \frac{cost_{j,av}{}^{hm}}{(1+r)^j}$
$PDVC_{avg}$	present discounted value of the lifetime stream of costs (including both heightened morbidity and premature mortality costs) associated with the illness for the "average individual" whose age of onset is av and who dies from the illness at n years post-diagnosis. $PDVC_{avg}$ is a simplification of $PDVEC_{av}$. It sets $ps_{j,av} = 1$ for $j<n$ and $ps_{j,av} = 0$ for $j \geq n$.	$PDVC_{avg} = \sum_{j=0}^{n-1} \frac{cost_{j,av}{}^{hm}}{(1+r)^j} + \frac{cost_{n,av}{}^{pm}}{(1+r)^n}$

The hypothetical example below considers an "average individual" who becomes ill at age 60 and who survives to age 68. The hypothetical incremental costs incurred by this individual at each year post-onset, the discounted age-specific costs, and the sum of these discounted costs (the present discounted value of this average individual's costs at the time of onset) are shown in the table below. Because the individual dies of the illness at age 68, the value of lost leisure time for each year that he or she would otherwise have lived is discounted back to age 68 and the discounted values summed ($95,009).

For those individuals who ultimately die of an illness, it could be argued that the value of a statistical life lost is the appropriate cost. This value would subsume the cost-of-illness estimate. Based on evidence from numerous value-of-life studies, the value of a statistical life far exceeds any cost-of-illness estimates that might be derived from estimates of the four cost components discussed above. For those individuals who do not die of the illness, there will be no terminal care costs, nor will there be any lost time or lost leisure time attributable to the individual dying prematurely. Costs incurred during a period of remission, however, could exceed those for terminal cases, if the remission period is substantially longer.

Table I.1.A-2: The Present Discounted Value of the Lifetime Stream of Hypothetical Costs of an Illness of a Hypothetical Average Individual

	Costs					
	Direct		Indirect			
Age	Medical	Nonmedical	Value of Lost Time	Value of Lost Leisure Time	Age-specific Costs	Discounted Age-specific Costs**
60*	$30,000	$5,000	$20,000	$7,000	$62,000	$62,000
61	$10,000	$5,000	$20,000	$7,000	$42,000	$40,000
62	$2,000	$1,000	$200	$0	$3,200	$2,902
63	$2,000	$1,000	$200	$0	$3,200	$2,764
64	$2,000	$1,000	$200	$0	$3,200	$2,633
65	$2,000	$1,000	$200	$0	$3,200	$2,507
66	$2,000	$1,000	$0	$200	$3,200	$2,388
67	$2,000	$1000	$0	$200	$3,200	$2,274
68	$40,000	$500	$0	$95,009	$135,509	$91,718
					Present discounted value of costs:	$209,187

*Average age of onset.
** Using a discount rate of 5 percent, discounted back to the age of onset. For example, to get the present discounted value (at age of onset) of the costs at age 63, these costs are divided by $(1+0.05)^3$